

ETHICS FORUM

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When It's Time to Stop Cancer Treatment: Helping Patients Prepare for Death

Sometimes, even when cancer therapy is working (that is, the patient shows a clinical or laboratory response), there comes a point at which the benefits of continuing aggressive treatment no longer outweigh the risks. Adverse effects of treatments, drug interactions, and comorbidities may contribute to the deterioration of a patient's overall condition, even as the cancer is held in check, and death may overtake the clinician's best efforts.

Careful consideration of the risks and benefits of treatment is a fundamental concept in health care. But in practice, it can be very difficult for patients, family members, and providers alike to recognize when aggressive therapy is no longer warranted and to agree on an approach to end-of-life care. No one wants to "give up," and it can be especially distressing to contemplate withdrawing a treatment that

is producing some measure of improvement.

The following case illustrates the complexity involved in making such a decision, as well as the need for open, honest, compassionate communication between provider, patient, and family members.

THE CASE

In March 2003, a 78-year-old, white man with chronic obstructive pulmonary disease, coronary artery disease, hyperlipidemia, gastroesophageal reflux disease, and benign prostatic hypertrophy was diagnosed with multiple myeloma (MM) at a non-VA hospital. His medical history included a previous myocardial infarction, which was treated with coronary artery bypass graft surgery, and an episode of deep vein thrombosis, for which he received low molecular weight heparin. His MM was treated initially with melphalan and prednisone, but after he developed febrile neutropenia, this chemotherapy regimen was discontinued.

In June 2003, the patient transferred his care to the VA health care system for financial reasons and was admitted to the Central Arkansas Veterans Healthcare System (CAVHS) in Little Rock for MM treatment. There, he began a com-

bination therapy of thalidomide and dexamethasone. Although this treatment resulted in a good clinical response (physicians observed a decrease in M protein levels), it was interrupted periodically by complications, including symptomatic, thalidomide-induced bradycardia and frequent urinary infections.

Over five months, the patient was admitted to the CAVHS several times for urosepsis due to bilateral nephrolithiasis, with follow-up conducted through the urology and hematology services. He underwent right ureteral stent placement in May 2004 and an open right lithotomy and left ureteral stent placement in July 2004. In August 2004, during another urosepsis admission, the patient had a cystoscopy, which prompted the urology service to recommend left ureteral stent removal.

Although this intervention, performed in September 2004, resulted in the resolution of sepsis, the patient's general health had deteriorated throughout the year. Despite multiple attempts to improve his nutritional status (including trials of mirtazapine, megestrol, and dronabinol), his nutritional intake had remained poor and he had lost over 50 lb. During his admission for

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left stent removal, his serum albumin level was 1.3 g/dL (down from 1.9 g/dL in May 2004) and his serum prealbumin level was 7.77 g/dL.

Concerned about his nutritional status, his family inquired about the possibility of percutaneous endoscopic gastrostomy (PEG) tube placement. The physicians recommended against this procedure, however, due to the patient's comorbidities and the possibility that a PEG tube would increase the probability of future infection. Although an evaluation of M protein levels showed that the patient's MM remained stable, his overall condition continued to worsen. At this point, his family asked whether hospice care would be appropriate.

BROACHING THE SUBJECT

When the overall condition of a patient with cancer worsens despite treatment, end-of-life care decisions need to be made,¹⁻³ even if laboratory test results appear promising. In many cases—as in the one described here—the patient or family brings up the subject. If they don't, however, it's up to the clinician to initiate the conversation.

Customarily, it's the physician in charge who would suggest to the patient and family that curative treatment is no longer helpful and that it may be necessary to accept the terminal nature of the condition. Many physicians, however, find this task extraordinarily difficult, since there is a natural inclination to view such an acknowledgment as a personal failure. Yet not being honest with oneself and one's patient and avoiding the situation only fosters fear and can make death and dying a horrifying experience rather than the sacred and blessed event it can be.^{4,5} For patients with a terminal disease, the

worst possible scenario would be to undergo unnecessary mental and physical hardship, futilely trying one aggressive therapy after another in the hopes of buying a little more time, when they could be using the time they have to begin the process of letting go of life.⁶⁻⁸

Giving the patient permission to stop treatment is important. Patients and family members need to understand that there are other goals to work toward when a cure is no longer an option. In addition to pain and symptom management, these include more spiritually oriented goals, such as finding inner peace.⁹⁻¹¹ People who develop spiritual strength during this difficult time are better equipped to deal with death and dying than those who are unprepared or who haven't seriously contemplated how they would like to die.

TRUTH AND COMPASSION: NOT MUTUALLY EXCLUSIVE

When approaching discussions of treatment failure, disease extension, and imminent death, veracity is the key ethical principle.¹² In our culture, the concept of truth telling doesn't always carry the same moral imperative as beneficence, justice, or respect. In fact, neither the Hippocratic oath, the World Medical Association's Declaration of Geneva, nor the American Medical Association's Principles of Medical Ethics mention it specifically.¹² When facing a dying patient, many providers feel that disclosing small amounts of information at a time, graded to the patient's requests, may be kinder than a total, abrupt declaration of the futility of treatment and the imminence of death. Under this concept, beneficence essentially trumps veracity as an ethical principle.

Although, as providers, we are not permitted (ethically or legally) to misrepresent the truth in any way with regard to research practices, diagnostic and treatment options, or other aspects of health care, there is no legal requirement in our current statutes to tell patients the *whole* truth. For example, in the case of *McGeshick v Choucair*, the court concluded that physicians are not obliged to inform a patient of all possible methods of diagnosis.¹³ And *Holt v Nelson* established that physicians need not disclose all possible treatment alternatives and consequences if the disclosure might have a detrimental effect on the patient's physical or psychological well-being.¹⁴

The extent of disclosure necessary or appropriate is judged by one of two professional medical standards. One of these holds physicians to the standard of what "a reasonably prudent physician" would disclose under the same or similar circumstances,¹⁵ while the other suggests that the duty to disclose is measured by the customary disclosure practices of physicians in the area.¹⁶ In both cases, the point is that physicians have a duty to disclose to their patients all material, foreseeable risks that treatments and procedures may pose. This stems from the belief that patients are the masters of their own bodies and, as such, they should be given enough information to allow them the freedom to make their own medical decisions.

In accordance with the intent of these standards, providers should strive to be open and honest with patients who are facing the end of life. In order for patients come to terms with their disease, make final arrangements, and "die a good death," it is necessary for providers

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to tell them truthfully, with compassion and sensitivity, when they are facing the terminal stage of an illness. It is one of the kindest and fairest acts that we can perform for our patients.

THE DECISION MAKING PROCESS

As with all health care decisions, those concerning end-of-life care should be based on sound medical reasoning and available evidence. In the case described here, the physicians expressed concern that PEG tube placement would expose the patient to further risks. Before a decision is made, the provider must be sure that the patient and family understand the benefits and risks of each option presented, as well as the provider's experiential recommendation. Patient autonomy is a fundamental ethical principle in health care, and ultimately, it is the patient who must decide—assuming he or she is able.

One part of protecting patient autonomy is ensuring that patients aren't being influenced unduly by family members or other loved ones whose wishes may not match their own. Even when patients appear to be making independent decisions, it's a good idea to talk to them apart from the family to ensure that they're not simply repeating the family's wishes. Another approach is to ask patients to what extent they rely on their family for decision making and to what extent they are willing to acquiesce to the family's decisions.

When patients lack the capability to make health care decisions, then a surrogate is needed to represent the patient.¹⁷ In many cases, this surrogate is named ahead of time or is implicitly known, as is usually the case for a spouse or next-of-kin. It's crucial for this sur-

rogate to understand that he or she is responsible for carrying out the patient's wishes. There may be times when what the surrogate believes would be best for the patient conflicts with what the patient would want. This distinction may be difficult to discern—and challenging for loved ones and even providers to accept.

If there's a chance that a patient can be returned to a functional level at which decision making is possible, the provider should make every effort to do so. In some cases, this may be achieved by treating pain or fatigue more effectively; in others, it may involve withdrawing a drug that's causing adverse effects. Providers also should consider the detrimental effects of poly-pharmacy, and try to reduce the drug load when appropriate.

MAKING TIME COUNT

There may be an urge—among patients, family members, or practitioners—to make more time, to try anything to prolong the patient's life. But at the end of life, the quantity of time is less important than the quality. Instead of measuring time, patients and family should be encouraged to focus on how it's spent: participating in a favorite hobby, being with friends and family, tying up "loose ends," attending special events, telling loved ones they are loved. These activities can bring closure to an entire lifetime.

By the same token, there is sometimes a lack of understanding of the need for everyone involved to take the time to make the ending count. A patient's lingering may seem to family members and caregivers like languishing. The tasks of caring, cleaning, and comforting can seem burdensome at times, and family caregivers may feel they're

neglecting themselves and other loved ones. Providers, too, need time to confront their own feelings of denial, fear, and lack of control and to accept the inevitable.

Although it's important not to waste time or avoid necessary conversations, time also can be an ally for patients and family members at the end of life. When the physical and mental stresses of terminal illness become overwhelming, postponing a discussion or leaving a problem alone for the moment may relieve tension and allow time for those involved to advance in their grieving toward acceptance. Such inner work takes place in the contemplative time between conversations, and therefore, conversations should be short and frequent.

THE "H WORD"

For many people (even providers) the introduction of the word "hospice" into a conversation brings to the surface feelings of hopelessness and dread because it signals the futility of further curative treatment. Studies show that physicians often are ill prepared for or uncomfortable with these discussions.^{4-6,18-20} Denial (on the part of the physician, patient, or family) may be a barrier. It's essential, however, for physicians to take the lead in overcoming this denial and fear so that they may help patients and family members view hospice care as a blessing instead of a curse.

Hospices have changed the way Americans experience dying.^{2,21-25} Prior to the 1970s, most patients with cancer in the United States died in a hospital. As the modern hospice movement took hold, however, the trend shifted toward more and more patients spending their last days at home or in a hospice facility. In the 1990s, the VA rec-

ognized the importance of hospice care and formally integrated it into its health care system.

Dying at home has many advantages, including familiar surroundings, proximity of family, and freedom from the structured hospital environment. Some people are uncomfortable with the idea, however, and for others, the lack of family caregivers makes it impossible.

For such individuals, admission to an inpatient hospice facility may be the best option. Most hospices are built in a natural setting in order to simulate the ancient tradition of "dying into nature." There are usually specialists in psychology and spirituality on staff to help patients make a peaceful transition to death, and there is a focus on meeting all comfort care needs. In many cases, patient rooms can accommodate family members so the patient can be surrounded by loved ones at all times.

Before entering a hospice program, patients and family members must come to a high level of acceptance, the final stage of grief. They are required to agree to forgo all further chemotherapy and radiation therapy, except that which is provided on a palliative basis. Although not a Medicare requirement, patients also generally agree to "do not resuscitate" orders.

A DISTURBING TREND

As rapid medical advances raise patient expectations for newer and more effective drugs, there has been a national increase in aggressive end-of-life treatment. A recent study by Earle and colleagues demonstrated that, among Medicare patients who died within one year of cancer diagnosis, rates of chemotherapy in the last three months of life increased signifi-

cantly from 27.9% in 1993 to 29.5% in 1996. Among patients treated with chemotherapy, the proportion of those still receiving treatment within two weeks of death rose from 13.9% to 18.5% over the same time period.²⁶ Other studies have yielded similar results.^{7,27,28}

Even more alarming, there is an increasing trend for patients to initiate hospice care only within the last three days of life. When hospice care was available locally, aggressive treatment at the very end of life was less common, suggesting a benefit of hospice beyond just comfort care.²⁶

Ethically speaking, the fair, compassionate, honest way to treat patients is to discourage aggressive treatment at the end of life. Patients deserve to know when they have limited time left, and they need to be given the freedom and support to decide how best to use this time. For most patients, this means finding a caring environment in which they can perform the act of dying surrounded by loving friends and family. ●

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